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ABSTRACT

This executive summary reviews results of a survey of 154 publicly-funded programs providing personal assistance services to disabled individuals. Introductory chapters identify the need for a national personal assistance program and policy, the concept of personal assistance and attendant services, the potential user population, and U.S. sources of funding. Key findings are reported in a section on survey results, focusing on the areas of program goals, number of programs per state, program age, administering agencies, funding sources, eligibility, services, hours of service availability, maximum amount of service allowed, types of service providers (individual providers, contract agency providers, and government agency providers), determination of services allowed, medical supervision, degree of program conformity to the Independent Living Model, program utilization and expenditures, availability of services across the United States, and the estimated need versus adequacy of the system to meet that need. Tables include, among others, "Programs with the Highest Independent Living Orientation," "Comparison Across States of Expenditures and Total Clients of Attendant Service Programs," and "Comparison of Home Care Survey Estimates of Need for Assistance with Number Actually Being Served." The report concludes with 17 recommendations to guide the development of national policy on personal assistance services. (JDD)

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ATTENDING TO AMERICA

PERSONAL ASSISTANCE FOR INDEPENDENT LIVING

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Executive Summary Of

THE NATIONAL SURVEY OF ATTENDANT SERVICES PROGRAMS IN THE UNITED STATES

World Institute on Disability
April 1987

EC 210 359

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EXECUTIVE SUMMARY

ATTENDING TO AMERICA:
PERSONAL ASSISTANCE FOR INDEPENDENT LIVING

A SURVEY OF ATTENDANT SERVICE PROGRAMS IN THE UNITED STATES FOR PEOPLE OF ALL AGES WITH DISABILITIES

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Simi Litvak
Berkeley, California
January, 1987

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* Individuals who use personal assistance services

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TABLE OF CONTENTS

ACKNOWLEDGEMENTS..... ii

LIST OF TABLES..... iv

LIST OF FIGURES..... v

PREFACE..... vi

Section

I INTRODUCTION..... 1

The Need for a National Personal Assistance Program and Policy..... 2
The Concept of Personal Assistance and Attendant Services..... 4
Potential User Population for Attendant Services..... 6
Sources of Funding for Attendant Services in the United States..... 8
Overview of the Survey..... 10

II SURVEY RESULTS..... 11

Program Goals, Administration and Funding..... 11
Program Structure..... 12
Service Providers..... 14
Degree of Program Conformity to the Independent Living Model..... 17
Program Utilization and Expenditures..... 18
Availability of Services Across the United States..... 24
Need vs. Adequacy of the System to Meet That Need..... 24

III CONCLUSIONS AND RECOMMENDATIONS..... 26

LIST OF TABLES

Table		Page
1	Provider Type Mix	14
2	Number of Benefits and Average Hourly Wage by Provider Type	14
3	Number of Programs Allowing Consumers to Train, Pay, and Hire and Fire Attendants	15
4	Circumstances in Which Programs Allow Relatives to be Paid Attendants	16
5	Programs with the Highest Independent Living Orientation	20
6	Comparison Across States of Expenditures and Total Clients of Attendant Service Programs	21
7	Total Expenditures on Attendant Services by Funding Source	23
8	Comparison of Home Care Survey Estimates of Need for Assistance with Personal Maintenance Tasks with Number Actually Being Served in Publicly Funded Programs from WID Survey	25

LIST OF FIGURES

Figure Page

1 Degree to Which Programs Conform to the Independent Living Model..... 19

PREFACE

By Irving Kenneth Zola, Ph.D.,
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Independence and self-reliance are strongly held American values. They are the key to any claim that we are a truly open society. For it is reasoned that if anyone would only try hard enough, s/he could eventually succeed -- the Horatio Alger myth. That such concepts have also crept into our rehabilitation literature should be no surprise. Thus traditional stories of successful rehabilitation continually stress the individual's ability to overcome his/her particular chronic disease or disability. In fact, success in rehabilitation is often equated with high scores on The Adaptation in Daily Living (ADL) scale, a scale that measures an individual's ability to do many personal care activities by him/ herself.

The founders of the Independent Living Movement scored poorly on the ADL scale. They were people on whom traditional providers of care had given up -- people for whom not only a productive life but even a meaningful one was deemed impossible. Neither they nor their families accepted the judgments of experts and in their struggle and their answer the Independent Living Movement was born. Their stories of success are different. Without negating the importance of personal qualities and the improvement of one's functional abilities, they emphasized the necessity of removing architectural barriers, changing societal attitudes, and using help whenever and wherever they could get it.

In all the years I've heard Ed Roberts speak (To those who don't know him, he's one of those "rejects" mentioned above -- a man, post-polio, who uses a respirator and a wheelchair and was deemed unworthy of California's rehabilitation dollars. He went on to co-found The California Center for Independent Living and later the World Institute on Disability and in-between became California's Director of the Department of Rehabilitation and a MacArthur Fellow) he has introduced his personal assistant by name and briefly detailed the latter's role in Ed's being "here." Ed makes the gesture to concretize a concept of independence which is a cornerstone of the Independent Living Movement (DeJong, 1983).

For Ed and others in the Independent Living Movement, independence is not measured by the quantity of tasks one can perform without assistance but the quality of life one can have with help. People have often gotten help from others but it was often given in the context of duty and charity (Scotch, 1984). Help in the context of Independent Living is instead given within the framework of a civil right and a service under the control of the recipient -- where, when, how and by whom.

This concept has long been argued about but little studied. DeJong (1977) surveyed the services of one state; DeJong and Wenker (1983) did a comparison of several; and Laurie (1977), a timely national overview. Within the last three years DeJong (1984) and Ratzka (1986) have provided in-depth descriptions of the progress and promise in the Netherlands and Sweden. This current report, prepared by Simi Litvak and sponsored by the World Institute on Disability, is a much needed American response -- a detailed survey of some 154 attendant service programs in the U.S. serving almost a million people.

The 17-page questionnaire measured their development, administration, funding sources, and degree of conformity to the ideal Independent Living Model. Despite the wealth of data, this report is no mere compilation of tables and statistics. It is an extraordinarily self-critical document, telling the reader what it gathered well, poorly, and not at all. It names names and articulates issues. While echoing the need for further information, in a series of recommendations it lays down the gauntlet of what must be done to make all our citizens independent. While documenting the programs already in existence, it also describes the underserved and points to the future (the ever increasing number of newborns with disabilities as well as increasing aging of our population). It is clear that many who will read this report will not at present have a disability. But if the data on aging and genetics are correct, it is unlikely that anyone reading it will not in their lifetime have to face the issue for him/herself or in his or her families.

At long last, we now have some baseline data. Personal Assistance for Independent Living lays down how far we have come and how far we have yet to go.

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SECTION I

INTRODUCTION

The need for community-based personal assistance services for independent living and the lack of a nationwide policy direction and mechanism for meeting that need has become an issue of major significance for disabled people of all ages who feel these services are critical to their ability to control their lives. Along with people who are disabled and their families, advocates, legislators and social policy makers throughout the United States and abroad have placed personal assistance services at home and in the community on the global agenda.

Personal assistance involves assistance with tasks aimed at maintaining well-being, personal appearance, comfort, safety and interactions within the community and society as a whole. In other words, personal assistance tasks are ones that individuals would normally do for themselves if they did not have a disability.[1] Central to this definition is the precept that personal assistance services should be controlled by the user to the maximum degree possible.

Our research leads to the conclusion that, for every person who is actually receiving community-based, publicly-funded personal assistance services, there are more than three people who need such services but who are not getting them. Specifically, we estimate -- on the basis of data from the National Health Interview Survey and surveys of the institutionalized population -- that 3.8 million people in this country need personal assistance services. According to the survey which is the subject of this report, however, only approximately 850,000 people currently receive personal maintenance and hygiene, mobility and household assistance services from publicly-funded, community-based programs. Thus, almost three million people in need are going unserved.

Moreover, almost all of the service programs which do exist are inadequate. Seldom do they offer the combination of personal

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[1] These tasks include: 1) personal maintenance and hygiene activities such as dressing, grooming, feeding, bathing, respiration, and toilet functions, including bowel, bladder, catheter and menstrual tasks; 2) mobility tasks such as getting into and out of bed, wheelchair or tub; 3) household maintenance tasks such as cleaning, shopping, meal preparation laundering and long term heavy cleaning and repairs; 4) infant and child related tasks such as bathing, diapering and feeding; 5) cognitive or life management activities such as money management, planning and decision making; 6) security-related services such as daily monitoring by phone; and 7) communication services such as interpreting for people with hearing or speech disabilities and reading for people with visual disabilities.

assistance services necessary to enable people who are disabled to function satisfactorily at home and in the community. Distribution of these programs is uneven across the United States, eligibility criteria vary widely, and direct service providers are generally poorly compensated.

Before discussing the results of the survey, it is important to make clear the particular philosophical orientation that has framed the conduct of the research and the interpretation of the results. What follows in this introduction then is the Independent Living view of personal assistance services, why they are needed, what they are and who can benefit from them. The World Institute on Disability (WID) is suited to present this view for several reasons. WID was established by several founders of both the Independent Living Movement and the first Center for Independent Living in Berkeley, California.

As a mechanism for obtaining input from other experts in the field during this study, WID established an Attendant Services Advisory Committee comprised of leading activists in the field and in the Independent Living Movement. Finally, at the request of the National Council on the Handicapped, WID played the major role in organizing the National Attendant Care Symposium held in July, 1985, under NCH sponsorship; most of the recommendations presented at the end of this report came out of that Symposium.

The Need for a National Personal Assistance Program and Policy

The need for personal assistance services has grown over the last few years. Due to advances in medical technology, there has been a sharp increase in the number of young people with extensive disabilities in the U.S. population. Many of these young people face a full lifetime in a nursing home, dependence upon their families until the parents became too old to provide the needed services, or dependence upon service programs that encourage dependence and poverty. This population has become the driving force behind the creation of the Independent Living Movement and its efforts to gain publicly-funded personal assistance services with maximum user control.

The ever-increasing number of people in the U.S. population who are old has expanded the disabled population needing personal assistance, since loss of functional ability (i.e. ability to perform activities of daily living) often accompanies the illnesses and injuries that occur more commonly among older people.

The demand for personal assistance services has also expanded as a result of the growing emphasis on keeping and taking disabled and elderly people out of institutions. This emphasis was largely born out of efforts by advocacy groups

representing people with a variety of disabilities (mental retardation and "mental illness" in particular) during the 1960's and gained strength with the emergence of perhaps its most natural adherent, the Independent Living Movement, in the 1970's.

It was clear to these activists that the successful deinstitutionalization of people with extensive disabilities, as well as the prevention of institutionalization and avoidance of dependency, rested substantially on the availability of personal assistance services in the community. However, the existing service system lacked a strong community-based orientation and did not offer services that foster independence.

The demand for personal assistance services has grown also because older people and their advocates are waging a struggle to develop a "continuum of long term care" where nursing homes are only one of several elements, rather than the primary locus of assistance for older people with functional limitations.

A fifth factor increasing the demand for personal assistance services has been the transformation of the U.S. family. A majority of working-age women now hold jobs outside the home. Rising divorce rates, shrinking family size and the growth in single-parent families have all contributed to the family's decreasing ability to provide personal assistance services for disabled members of all ages.

Finally, during the late 1970's and early 1980's, the federal and state governments became very interested in the replacement of institutional care by community-based services, which include personal assistance services, because this seemed to be a more economical way to treat disabled people unable to manage completely for themselves.

The need for community-based personal assistance services, then, is clearly on the national agenda. Despite the growing need and interest, however, the federal government has neither promoted the development of these services nor established a coherent policy on the issue. Jurisdiction over various personal assistance programs and policies is divided among numerous federal agencies and congressional committees. There is no coordinated "system".

In the absence of a comprehensive federal policy and funding for personal assistance services, some states have tried to piece together several federal funding sources into a state program; a few other states have tried to meet the need by developing their own policy and program; still other states have done nothing in the area and, as a result, have almost no personal assistance services available.

The lack of a comprehensive, coordinated national policy often means that, even where the services are available, users

either have to maneuver through a fragmented maze of service programs in order to put together a package of required services, make do with services that are inadequate, or remain in an institution, nursing home, or isolated at home with their families.

In addition, those programs that do exist usually provide assistants only for poor people. This means that people either need to have incomes below the poverty level or earn enough not only to support themselves but also to pay for the assistance that they need as well. The resulting need to earn a relatively high income thus discourages people from working, thereby increasing, rather than decreasing, public expenditures on the disabled.

The Concept of Personal Assistance and Attendant Services

This report covers solely attendant services. Attendant services are a subset of the full range of personal assistance services disabled people need to function independently in the community (see footnote 1, page 1). Attendant services include assistance with personal maintenance, mobility and household maintenance tasks. Often these services are separated into groups and offered by separate programs. To compound the confusion, they are called by other names as well: personal care services, personal care attendant services, home health aide services, homemaker services, chore services.[2]

Our conception of appropriate personal assistance services goes much deeper than a simple listing of tasks, however. Of major importance is that personal assistance service users have the opportunity, if desired, to exercise as much control as they are capable of handling over the direction and provision of these services - i.e. who does them, how, and when. This element of self-determination lies at the core of the Independent Living model of service delivery. The model rests on the philosophy that to be independent means to be empowered and self-directed. Independence does not mean that one must be able to perform all tasks alone without help from another human being. This distinction may appear to some as not very significant, but it is absolutely crucial for people of all ages with extensive disabilities. Such individuals may be able to perform few if any

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[2] In discussing and defining personal assistance and attendant services, we deliberately avoid the use of the term "care" (e.g. attendant care, personal care, etc.) because it implies that the disabled person passively receives the ministrations of the attendant. In our view, care is what sick people receive. Disabled people are not sick and, therefore, do not need "care". They need an assistant.

daily living tasks without assistance, but this fact has no bearing on their right to determine when, where and how these tasks are performed. For people who are unable or unwilling to totally direct their own services, the option to receive services from assistants trained and supervised by a public or private agency should be available.

In addition, personal assistance services are personal assistance services even when they are performed by members of one's family. Consequently, family members who provide such services at the request of the user should be entitled to receive compensation for their labor. People with extensive disabilities may require 20 or more hours of assistance per week, the equivalent of a half-time job. This amount of assistance, which is quite beyond what family members would do for each other if none were disabled, clearly cuts into the time that would otherwise be available for outside employment and other familial duties. The vast majority of people who provide volunteer personal assistance in the U.S. are women, a situation which increases the incidence of poverty among women. Clearly, substantial governmental expenditures are often avoided when families maintain disabled members outside of institutions, but providing these services on a volunteer basis often entails considerable costs: the family's earning potential is significantly reduced and the person with a disability is inhibited from achieving full independence. Having to depend upon the charity or good will of family and friends places the user in a dependent rather than an independent position. In addition, when family members are forced by economic or other reasons to provide attendant services, the resulting stress can lead to psychological or physical abuse of the person who is disabled.

The Independent Living conception of attendant services also recognizes the need to include in regular service delivery systems both emergency and short term services, commonly referred to as respite. Emergency attendant services provide assistants in cases of emergency, for example when attendants cannot perform their duties because of sickness or personal difficulties and not enough notice can be given to make other arrangements. In cases where a disabled individual lives alone and has no relatives or friends who can help out at the last minute, emergency back-up services are crucial.

Short term services are intermittent attendant services replacing family members or regular assistants on a scheduled basis. They enable the individual who is disabled to get both the assistance needed and an opportunity to be independent of the family for brief periods. Short term personal assistance also allows the family member to leave the home for anything from a

few hours for errands to an evening out or several weeks' vacation.[3]

In summary, while we recognize that personal assistance services by themselves are not sufficient to enable people with disabilities to live to their maximum potential in the community, they are absolutely necessary to achievement of this goal.

Potential User Population for Attendant Services

The population of potential users of attendant services is large and diverse. It includes people of any age and with any disability - be it physical, sensory, intellectual or mental- which results in long-term functional limitations that impair an individual's ability to maintain independence.

The perception of who can use personal assistance has evolved over the years. It has long been generally accepted that people with physical disabilities often need assistance. More recently, however, people with mental or intellectual disabilities but no physical limitations have also begun to use assistants to help them function effectively in the community. Such assistants may help people pay bills, keep financial records, make up shopping lists, deal with landlords, etc.

The user population includes people of all ages. There has been a tendency to treat older people with functional limitations, disabled working age people and disabled children as three distinct groups with totally different service needs. However, older people who have functional limitations are disabled in the same sense that other disabled people are - that is, they are limited in their ability to perform life-

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[3] Short term services are part of the continuum of personal assistance services. Some people need these services daily, some need them several times a week and others need services on occasions when family members have to leave the home. Short term services serve the person who is disabled, breaking the chain of mutual dependency between the disabled family member of any age and the rest of the family. Power dynamics in families can be changed by another person coming into the home for brief periods. Because families may have to provide major amounts of service, the disabled individual may be made the victim of the family's stress. In these situations, the disabled individual needs a break from the family and the routine equally as much as the family. Short term personal assistance should be seen as an opportunity for the disabled individual to get out of the house, go on visits, see a film or even take a trip. Usually the family uses these services to go away and the disabled persons stays at home or - even worse - is sent to a hospital.

maintaining tasks without assistance. Whether young, middle-aged or old, disabled people may be at risk of isolation, physical harm and institutionalization because of their functional limitations. The causes of these limitations may vary somewhat, but the effects are often very similar. Furthermore, older people with functional limitations have as much need to maintain control over their lives and the services they receive as younger people with disabilities. Thus, not only are personal assistance services often the appropriate answer for many older people with functional limitations or disabilities, but the principles of the Independent Living Movement apply to them as well.

If personal assistance has not been widely recognized as a means of preserving older people's independence, the use of non-family paid providers to foster independence in disabled children has hardly even been considered. Making such assistance available has several benefits. It can alleviate financial pressure on families by allowing parents to take outside employment. This is particularly true in cases where a child with a disability needs assistance throughout the day and there are no volunteer resources available.

Personal assistants for children can relieve the emotional strain that frequently develops within families as siblings (and sometimes parents) come to resent the disproportionate amount of time that parents must devote to a child who is disabled.

Providing personal assistants for children with disabilities also allows them a more normal process of development and maturation. It enables them to go places (thus gradually expanding their range of mobility), engage in recreational pursuits, and - particularly important during adolescence- interact with peers. Also, children with disabilities, assisted by an attendant, can begin taking on family chores and duties- such as setting the table or taking out the garbage - just as non-disabled children do as a normal part of growing up.

This list of benefits of providing attendants for children could go on and on. The primary point, however, is that the process of developing one's independence and self-management skills commences long before a person with a disability reaches adulthood. It is a process that occurs throughout the normal course of development of all children.

The population of potential attendant service users also includes people in various living arrangements and settings. People with functional limitations who live independently obviously need assistance. People living with their families also need assistance; whether in the form of occasional short-term service or on a regular basis, so that the disabled person has more independence and the family member, relieved of attendant duties, is free to work and/or maintain the home.

Attendants may also work for clients in various congregate living arrangements such as cluster housing and group homes. In these situations, attendants may be shared by several people, though this type of arrangement has drawbacks because it frequently means that the individual user loses control over when and how long the attendant is available. Finally, people can use personal assistance not only at home, but also at work, recreation and travel.

Corollary to this inclusive definition of who can benefit from personal assistance services is the understanding that a person's medical diagnosis has no bearing on his or her need for services. People with similar diagnoses may have dissimilar functional abilities and face different sets of environmental constraints. Determination of need for personal assistance is more appropriately based on a functional assessment which measures one's abilities and limitations in performing necessary activities of daily living within a particular environment.

Source of Funding for Attendant Services in the U.S.

Several federal and state programs currently provide funding and authorization for some part of the constellation of personal assistance services.

Medicaid: The bulk of Medicaid funds go toward hospital, nursing home and institutional care for low income people. There are wide variations from state to state in home and community-based service benefits offered and the groups covered, income eligibility criteria, cost sharing formulae and levels of provider reimbursement for home and community-based services. Almost all Medicaid home-delivered service programs are geared toward medically related services, the major exceptions being the Colorado, Massachusetts and New York programs which have found innovative ways to work within the Medicaid framework and still make it possible for individuals who are disabled to maintain a great deal of control.

Title XX - Social Services Block Grant (SSBG): Most states provide some sort of home based services with Social Services Block Grant funds, but few have developed comprehensive SSBG attendant services programs which encompass personal maintenance, hygiene, mobility and household assistance. California's In-home supportive services system (IHSS), with expenditures of $370 million in FY85-86 and a caseload of 111,300, is a notable exception.

Older Americans Act - Title III: Title III was designed to augment existing services and to develop new ones to meet the needs of people over 60. Included in these services are a very wide variety of personal assistance services. Federal

regulations encourage the targeting of Title III funds to the poor. Because of funding limitations, however, it has not been a major source of attendant services.

Home and Community-Based Service Waivers: The Home and Community-Based Service Waivers - commonly known as Medicaid Waivers - were developed in 1979 to investigate ways to halt the growth of Medicaid nursing home and institutional expenditures by expanding home and community services for people with physical and intellectual disabilities, children, and older people.

An assumption underlying the waiver programs is that home and community-based services are less costly than institutional services. However, the Health Care Financing Administration (HCFA) argues that, since the number of people who would ordinarily be in a nursing home is limited to the number of nursing home beds which exist in any particular state (an amount which varies widely), then the number of people on the waiver must be limited to those who quite literally would be admitted to a nursing home if it weren't for the waiver. Since those who aren't admitted because of bed shortages somehow get their needs met in other settings by family and friends, the argument goes, the federal government has no responsibility to maintain these people.

In addition, the federal government required states not to spend on any one individual more than the average cost of what it takes to maintain people in nursing homes, less a certain percentage for room-and-board costs. This rule discriminated against people with extensive disabilities because the bulk of people in nursing homes are older people with fewer service needs and presumably lower average service costs. Responding to pressure, Congress has now changed this rule so that there is a two-tiered limit - one tier being the average cost of maintaining physically disabled people and the other the average cost of maintaining other nursing home residents. Contention over who can be covered by a Waiver has greatly slowed the pace of new Waiver approval and renewal of old ones by HCFA.

State and Locally Funded Programs: During the late 70's and 80's a number of states created programs funded entirely by state and local sources. Because these programs did not use federal dollars, they could allow disabled people to hire, train and, if necessary, fire their own assistants and also contained realistic cost-sharing formulae that allowed people with disabilities to work and still receive a personal assistant subsidy payment.

Veterans' Aid and Attendance Allowance: An "aid and attendance allowance" is furnished to veterans in addition to their monthly compensation for disability incurred during active service in the line of duty.

Overview of the Survey

This report is based on the results of a survey - conducted by mail or telephone from February 1985 to January 1986 - of administrators of every program in the United States (excluding Puerto Rico and the trust territories) which provided personal maintenance/hygiene and/or household assistance services on either a regular or respite basis to disabled people of any age.[4]

One-hundred seventy-three programs meeting these criteria were identified. Nineteen of these, for various reasons, are not included in the results presented here.

The questions addressed by WID's survey and by this report are the following:

1. What are the goals of the programs and how are they structured? What are their administering agencies, funding sources and eligibility criteria? What services are provided and who provides them?

2. How do the scope and quality of the service programs measure up? In particular, how well do they meet the criteria for an adequate attendant services system developed by the participants at the July 1985 conference in Washington, D.C. sponsored by the National Council on the Handicapped in conjunction with the World Institute on Disability?

3. Where do programs fall along the continuum between the Independent Living and medical models?

4. What is the degree of attendant service utilization, i.e. how many people are currently receiving some type of attendant services? How does this number compare to the number of people who could benefit from such services?

5. Are attendant services equitably distributed across the U.S.?

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[4] This survey did not, however, include programs which served exclusively people with mental disabilities (commonly termed "mental illness") and/or people with intellectual disabilities (mental retardation and similar conditions). Because of fragmentation of the service system, these programs are administered separately and would have required substantial additional resources to locate and survey.

SECTION II

SURVEY RESULTS

Program Goals, Administration and Funding

Program Goals

96% of the programs are directed at preventing institutionalization by making it possible to keep people in their own homes or communities.

66% of the programs are directed at containing the cost of long term care.

Only 10% of the programs are aimed at allowing people to work.

Number per State

Every state has a personal assistance service program of some sort. (This does not mean, however, that anywhere near all the people who need services are being served. Indeed, in all but a few states, most people in need of services are not getting them.)

On the average, there are three programs per state. The range is from one program in Arizona, Louisiana, North Dakota and Tennessee, to 6 each in Massachusetts, Missouri, New York and Ohio.

Program Age

The programs range in age from 32 years old to less than one year old.

56% of the programs were started after 1980. Almost half of these are waiver programs.

Administering Agencies

45% are administered by state level agencies having jurisdiction over welfare and social service programs. An additional 17% are administered by medical assistance and health departments.

27% are administered by State Areas on Aging.

State vocational rehabilitation agencies administer 7% of the programs.

Personal assistance services programs are administered directly by independent living programs in Maine, Nevada, North Carolina and South Dakota.

Funding Sources

More than 1/3 rely on Medicaid funds combined with state and, in some cases, local funds.

Less than 1/4 use Social Services Block Grant funds.

22% are funded entirely from state or local sources.

Only 8% of the programs function on a combination of federal funding sources.

Program Structure

Eligibility

Age

88% of programs serve people over 60 or 65 years old, 72% serve adults between ages of 18 and 64; and 45% serve children. 41% serve people of all ages.

Disability Groups

56% serve people with all types of disabilities. 26% serve only people with physical disabilities and those with brain injuries. 10% serve only those with physical disabilities.

Employment

16 programs encourage people to work; 6 require an individual to be employed; and 4 require that the person be employed a minimum of 20 hours a week.

Income

An estimated 50% of the programs had income limits at or below $5,250 (the U.S. poverty level for a single person in 1985). 36% of the programs have a graduated shared cost formula.

Other Eligibility Criteria

57% required that people be at risk of institutionalization, 42% required physician's orders.

Services

The basic minimum of personal maintenance and hygiene services are defined as feeding, bathing, dressing, bowel and bladder care, oral hygiene and grooming and transfers. The basic minimum of household maintenance services is light cleaning, laundry, shopping, and meal preparation and clean-up. The combination of these household and personal services makes up a basic attendant service program.

Ninety (58%) of the programs surveyed offered attendant services. Of these, 51 also offered catheter assistance.
12% offer personal services only.

25% offer household maintenance services only.

5% offer only respite services, but more than half of the programs included some sort of respite service.

Hours services available

101 (66%) of the programs offered services 7 days a week, 24 hours a day.

18 (12%) offered services 7 days a week, but less than 24 hours a day.

24 (16%) of the programs offered services less than 7 days a week and less than 24 hours a day.

Maximum amount of service allowed

Service maximums per user were expressed in hours or in terms of a maximum financial allowance.

54 (35%) of the programs expressed the limit in monetary terms with a range of $60/month to $1,752/month. The average was $838.

38 (27%) programs gave the maximum allowance in terms of hours. Hours ranged from 3 to 67/week with an average of 29 hours.

44 (29%) programs set no maximum monthly allowance.

Service Providers

Assistants can be divided into three groups, those who are individual providers, those who work for contract agencies and those who work for state, county or municipal governments. Many programs use more than one type of provider (Table 1).

TABLE 1

PROVIDER TYPE MIX (n=154)

Type of Provider	Programs Number	Programs Percent
Contract Agencies Only	54	35%
Individual Providers Only	33	21%
IPs and Contract Agencies	24	16%
IPs, Contract & Govt Staff	20	13%
Contract Agencies & Govt Staff	20	13%
Government Staff Only	3	2%

Provider types vary in terms of benefits and wages (Table 2).

TABLE 2

NUMBER OF BENEFITS AND AVERAGE HOURLY WAGE BY PROVIDER TYPE[a]

Provider Type	Average Hourly Wage	Benefits Average Number	Benefits Range[a]	Benefits Mode
Government Workers (n=30)	$4.77	4.7	0-7	7
Contract Agency Workers (n=62)	$4.71	1.7	0-7	0
Individual Providers (n=60)	$3.74	.7	0-3	0

[a]Includes 1) vacation pay, 2) sick leave, 3) health insurance, 4) worker's compensation, 5) Social Security, 6) unemployment compensation and 7) transportation costs.

Provider modes vary in terms of the degree of consumer control allowed to train, pay, hire and fire attendant (Table 3).

TABLE 3

NUMBER OF PROGRAMS ALLOWING CONSUMERS
TO TRAIN, PAY, AND HIRE AND FIRE ATTENDANTS

Type of Provider	Train		Hire/Fire		Pay	
	#	%	#	%	#	%
Individual Providers (n=77)	48	62%	57	74%	31	40%
Contract Agencies (n=118)	15	13%	5	4%	1	1%
Government Workers (n=44)	4	9%	4	9%	0	0%

Individual Providers

A major advantage of the Individual provider mode, from the Independent Living Movement's perspective, is that it often gives more control to the consumer.

The primary disadvantage of the individual provider mode is that workers tend to be paid at or very close to the minimum wage, receive very few it any benefits and have a high turnover rate. Some administrators were opposed to the consumer taking charge of the training function because of potential liability problems, even though in 27 years of experience the California system (which does not require any training) has never been sued for negligence related to an independent provider.

Most of the individual provider programs have minimal regulations regarding providers. 22 required some formal training for assistants, 27 required assistants to be 18 or older. 26% of the programs said that the only requirement is that the consumer request an individual provider.

41 programs permit relatives to be paid under some circumstances (Table 4).

TABLE 4

CIRCUMSTANCES IN WHICH PROGRAMS ALLOW RELATIVES TO BE PAID ATTENDANTS (n=41)

Reason	Number	Percent
No one else is capable or available	13	31%
The relative is not legally responsible for the disabled individual	10	24%
Relative is prevented from working outside the home because no other attendant is available	9	22%
Relative does not reside in the same house	7	17%
Relative is not the spouse	7	17%
Any relative is okay	6	15%
No spouse, parent, child or son/daughter-in-law	4	10%
Niece, nephew, cousin okay	2	5%
No blood relatives or spouses	2	5%

Contract Agency Providers

The average hourly difference between the reimbursement rate and the attendant's wages was $4.08, almost a 100% mark-up for every hour of service.

Contract agency workers are usually trained. Trained assistants are appropriate for disabled clients who are unable to manage totally their personal assistant.

Government Agency Providers

Only 29% of programs utilize direct employees of the state or local government units and the number will probably decline further.

Determination of Services Allowed

Functional ability and services needed are the primary indicators used for evaluating the client. Service professionals, including case managers, social workers, nurses and program directors, were

found to be the primary decision makers. Users have a voice in these decisions in only 11 (7%) of the programs.

Medical Supervision

25% of the programs require medical supervision by an R.N. or other health professional for all services.

33% of the programs require medical supervision for some services.

40% of the programs require no medical supervision.

Degree of Program Conformity to the Independent Living Model

Attendant programs can be arranged on a continuum defined by the medical model on one end and the Independent Living Model on the other. In the Medical Model a physician's plan of treatment is required along with periodic nursing supervision. Attendants are recruited by the contract agency. The attendant is ultimately accountable to the physician and the recipient essentially plays the role of patient.

In the Independent Living Model the attendant is managed by the user. No medical supervision is required. Attendants are recruited by the user, paid by the user and accountable to the user.

In order to see where the programs surveyed fit on the continuum, each program was given a score from zero to ten based on a count of how many of the following ten characteristics of the pure Independent Living Model the program incorporated:

1. No medical supervision is required;
2. The service provided is attendant service with catheterization, i.e. services offered include personal maintenance and hygiene, mobility and household assistance.
3. The maximum service limit exceeds 20 hours per week;
4. Service is available 24 hours a day, seven days a week;
5. The income limit is greater than 150% of the poverty level;
6. Individual Providers can be utilized by the consumer;
7. The consumer hires and fires the attendant;

8. The consumer pays the attendant;

9. The consumer trains the attendant.

10. The consumer participates in deciding on the number of hours and type of service he or she requires.

Figure 1 shows the distribution of the surveyed attendant programs along the continuum from Medical Model to Independent Living Model. Half of the states have programs that score 7 or better on the Independent Living Orientation Scale (Table 5). But, at the same time, it must be pointed out that half of the programs have scores of three or less.

Program Utilization and Expenditures

Number Served

Approximately 850,000 people received publicly-funded attendant services through 135 of the programs in the WID Survey. (This figure is an estimate because 16 programs could not report their caseload, 19 programs could not be interviewed, 9 programs were eliminated because the agency could not isolate figures for attendant services from other services, and two programs provided figures too late for inclusion.)

The proportion of the population receiving attendant services in any given state ranged from 0.01% to 0.87% of the population (Table 6). The total number of users represents 0.34% of the U.S.population.

Disabilities of People Served

Forty-six percent of the programs actually serve people with all types of disabilities; 28% served only people with physical disabilities and/or brain injury. Thirteen percent served only people with physical disabilities. These figures do not vary greatly from what administrators say programs will serve.

Ages of People Served

Twenty-three percent (142,562) of the people served are less than age 60 or 65. Seventy-seven percent (476,851) of those served are older than age 60 or 65.

DEGREE TO WHICH PROGRAMS CONFORM TO INDEPENDENT LIVING MODEL (n=147)

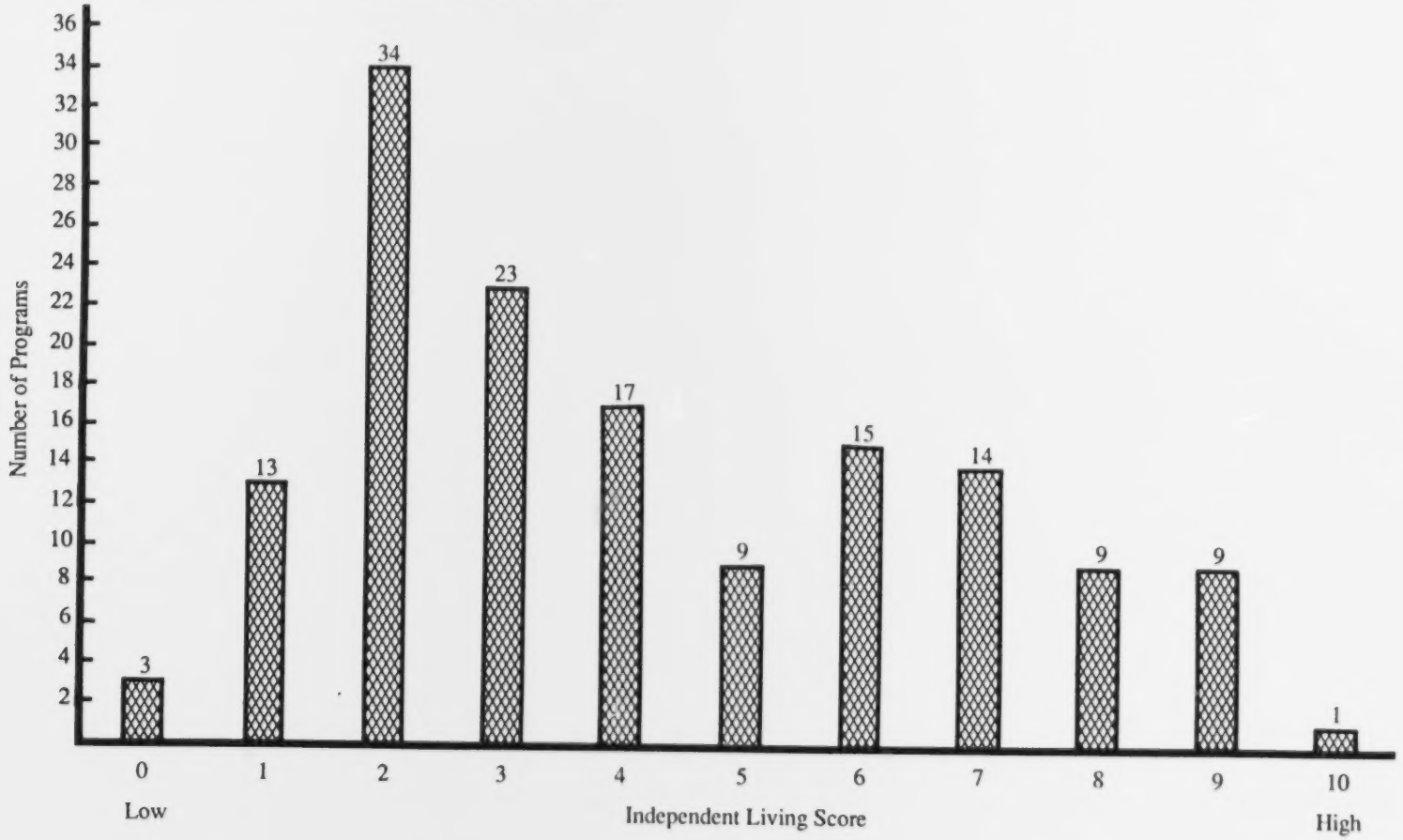

Figure 1

19

TABLE 5

PROGRAMS WITH THE HIGHEST INDEPENDENT LIVING ORIENTATION

Rating	State	Program Name
10	Pennsylvania	Attendant Care Demonstration
9	Maine	Home and Community-Based Waiver
	Maine	Homebased Care Program
	Missouri	Personal Care Assistance Program
	Nevada	Attendant Care Program
	Ohio	Personal Care Assistance Program
	South Dakota	Attendant Care Program
	Utah	Personal Attendant Care
	Vermont	Participant Directed Attendant Care
	Washington	Chore Services
8	Kentucky	Personal Care Attendant Program
	Maine	Attendants for Employed People
	Maryland	Attendant Care Program
	Michigan	Home Help
	Mississippi	Independent Living-A/C Pilot Pgrm
	Nebraska	Disabled Persons/Family Support
	New Hampshire	Adult Services
	Pennsylvania	A/C Services for Older Adults
	South Dakota	Attendant Care
7	Alabama	Optional Supplement of SSI
	Arkansas	Spinal Cord Commission
	California	In-Home Supportive Services Pgrm
	Connecticut	Essential Services Program
	Connecticut	Personal Care Assistance Program
	Illinois	Community Care Program
	Illinois	Home Services Program
	Maine	Attendants for Unemployed People
	Massachusetts	Independent Living Personal Care
	Massachusetts	Personal Care Program
	North Carolina	Attendant Care
	Oregon	In-Home Services/Project Independ.
	Wisconsin	Supportive Homecare Program
	Wisconsin	Family Support Program

TABLE 6
COMPARISON ACROSS STATES
OF EXPENDITURES AND TOTAL CLIENTS
OF ATTENDANT SERVICE PROGRAMS[a]

State	Total Number of Attendant Service Clients	Percentage of 1985 State Population Estimate	Total Expenditures (in thousands)
Alabama	24,016	.62%	$ 17,723
Alaska[b,d]	1,193	.30%	2,200
Arizona	1,500	.06%	1,696
Arkansas	5,225	.23%	10,285
California	150,805	.64%	345,445
Colorado[g]	8,867	.31%	14,719
Connecticut	10,816	.35%	23,108
Delaware	968	.16%	1,485
Florida[b,f]	22,858	.24%	21,386
Georgia[a]	6,747	.12%	7,612
Hawaii	1,709	.18%	2,875
Idaho	4,283	.45%	1,177
Illinois	16,301	.14%	33,734
Indiana	21,808	.40%	13,391
Iowa	12,605	.43%	7,849
Kansas[b]	9,057	.38%	6,137
Kentucky	7,329	.20%	6,065
Louisiana[c]			
Maine	6,013	.53%	4,804
Maryland	5,082	.12%	11,441
Massachusetts[b,d]	46,374	.81%	90,467
Michigan	43,933	.47%	69,653
Minnesota[e]	35,300	.87%	5,800
Mississippi	400	.02%	372
Missouri	31,209	.63%	14,659
Montana	6,248	.79%	1,969
Nebraska	5,429	.35%	3,286
Nevada	1,071	.13%	1,092
New Hampshire	3,893	.42%	3,087

State	Total Number of Attendant Service Clients	Percentage of 1985 State Population Estimate	Total Expenditures (in thousands)
New Jersey	1,850	.03%	3,809
New Mexico	2,200	.17%	7,384
New York	124,808	.71%	504,361
North Carolina	626	.01%	1,657
North Dakota	59	.01%	192
Ohio	26,359	.24%	46,942
Oklahoma	9,130	.30%	35,395
Oregon	10,041	.38%	15,330
Pennsylvania	59,995	.51%	22,338
Rhode Island	1,578	.17%	3,754
South Carolina	9,690	.31%	14,501
South Dakota	4,020	.58%	1,910
Tennessee[b]			875
Texas	68,880	.48%	108,288
Utah	522	.04%	1,048
Vermont	362	.07%	611
Virginia	5,000	.09%	14,191
Washington	10,167	.25%	22,735
West Virginia[a]	5,177	.27%	4,814
Wisconsin	15,600	.33%	25,953
Wyoming[c]			
Dist.of Columbia	3,285	.55%	8,853
TOTAL	850,388		$1,568,458

[a] Data added from two additional programs from questionnaires received late from Georgia and West Virginia.
[b] Number does not include Title III recipients because administrator unable to isolate attendant services from adult day care, home-delivered meals, counseling and other Title III services.
[c] No data available.
[d] Alaska & Massachusetts figures do not include HHA programs. Decided they were strictly short-term.
[e] Minnesota does not include Personal Care Services figures.
[f] Florida does not include elderly waiver.
[g] Colorado does not include HHA program/could not separate ILP-delivered services from regular Medicaid program.

Expenditures

Total expenditures were approximately $1.6 billion, ranging from a low of $2,000 (a program serving 10 people) to a high of $458 million (a program serving 52,400 people). Average yearly expenditure per client was $2,862, with the median being $1,421.

As Table 6 shows, New York has the highest expenditure even though California serves the largest number. This reflects the fact that New York relies heavily on contract agencies whereas California uses more individual providers.

Expenditures by Funding Source

TABLE 7

TOTAL EXPENDITURES ON ATTENDANT SERVICES
BY FUNDING SOURCE (n=129)

Funding Source	$	%
Federal		
Title XIX		
Regular Program	384,740,000	25%
Waivers	19,294,000	1%
Title XX	320,703,000	21%
Title III	37,281,000	2%
Title VIIA	14,000	0%
Other Federal	52,372,000	3%
TOTAL FEDERAL	814,404,000	52%
Non-Federal		
State	617,732,000	40%
County/Municipal	84,438,000	6%
Other	13,004,000	1%
Client Fees	7,166,000	0%
Private	1,035,000	0%
TOTAL NON-FEDERAL	723,375,000	48%
GRAND TOTAL	1,537,779,000	100%

Expenditures on Attendant Services Not in the WID Survey

The Veteran's Administration aid and attendance allowance program paid $101 million to 8,493 veterans in 1984.

Some Developmental Disability and Mental Health Service funds are utilized to maintain individuals outside of institutions.

Many individuals who are disabled receive services from family and friends free of charge or pay for the services out of pocket.

No private health insurer pays for attendant services on a long term basis.

Availability of Services Across the United States

In 8 states, the full range of publicly-funded attendant services are not available for people with disabilities of any age. In 3 states services are available for some people but not others, depending on age.

In 39 states plus the District of Columbia, programs exist that offer attendant services to all age groups. These programs differ widely in their capacity to meet the needs of disabled people in their jurisdiction because of marked variations in eligibility criteria, services offered, maximum allowances, other rules and regulations, and, most importantly, funding constraints.

Thirty-four states have short term or respite available for all age groups, though the quality and quantity of the services available is not equivalent across these programs.

Need vs. Adequacy of the System to Meet That Need

Conducted by the U.S. Bureau of the Census, the Home Care Supplement to the 1979-1980 National Health Interview Survey (NHIS) interviewed a sample of civilian, non-institutionalized people in the U.S. over a period of two years. Respondents were asked whether they received or needed the assistance of another person in performing seven basic physical activities: walking, going outside, bathing, dressing, using the toilet, getting in or out of bed or chair, and eating.

Table 8 compares the NHIS estimates of need with the WID data on the number of people being served. This comparison indicates that 74,473 children who need personal assistance services do not get them from the public programs surveyed for this study. There are an estimated 758,938 working-age adults

and 903,202 people 65 or older who need assistance but do not get it from public programs. All told, then, there are an estimated 2,134,111 non-institutionalized people who need personal assistance but do not receive it from publicly-funded attendant service programs.

If veterans are subtracted and an estimate of institutionalized people who could live at home with adequate personal assistance is added, then the number of people who may not be receiving community-based publicly supported attendant services who could benefit from such services could be estimated at 2,975,618 (3 million).

TABLE 8

COMPARISON OF HOME CARE SURVEY ESTIMATES
OF NEED FOR ASSISTANCE WITH PERSONAL MAINTENANCE TASKS
WITH NUMBER ACTUALLY BEING SERVED IN PUBLICLY FUNDED PROGRAMS
FROM WID SURVEY

Age Group	1984 Total U.S. Population	Home Care Survey		WID Survey	
		% Needing Help With 1 or More Tasks	# Needing Help With 1 or More Tasks	% Being Served	# Being Served (FY84)
Children (17 & under)	62,688,000 (under 17)	.23%	144,182	.10% (under 18)	59,527
Adults (18-64)	145,430,000 (17-64)	.667%	970,018	.09% (18-60 or 65)	136,062
Aging (65+)	28,040,000 (65+)	6.67%	1,870,268	2.34% (60 or 65+)	654,798

The average cost per user of attendant services from the WID study amounts to $2,840 for all types of service. If this figure is multiplied by the estimated number of people not being served, 3 million, then the additional expense could be estimated to be approximately $8.5 billion.

SECTION III

CONCLUSIONS AND RECOMMENDATIONS

As this study clearly indicates, there is no comprehensive system of attendant services in the United States. There is no broad federal policy, rather, scattered references to personal assistance services are found embedded in policies established by Congress and federal agencies with respect to programs such as Medicaid and the Older Americans Act. Consequently, jurisdiction over federal personal assistance programs is divided among several different agencies. The programs that exist are funded by a wide variety of federal and non-federal sources. Responding to what they perceive as a major need, states have developed their own policies and programs, usually (but not always) making use of those disparate federal funding sources that are available. States have generally failed to benefit from the experience of other states, apparently because until recently there has been little if any communication between them. All this has resulted in personal assistance services which are fragmented, lack coordination, usually medically oriented, burdened with work disincentives, inequitably distributed across the United States, and delivered by personal assistants who are poorly paid.

The lack of a federal personal assistance policy has affected the lives of many of the 3.8 million Americans of all ages with disabilities who presently are either receiving personal assistance services which may be inadequate or who are receiving no publicly funded services at all. Many of these people are denied independent lives because they are forced to either 1) depend on relatives and other volunteers for personal assistance, 2) live in institutions because no community-based personal assistance services are available, or 3) make do with less than adequate services from a variety of providers over whose services they have little or no control.

The World Institute on Disability is committed to working with people throughout the country towards the establishment of a comprehensive, funded National personal assistance policy. We know how critical these services are to people with disabilities everywhere, and from our first hand experience in California, we have seen the benefits such services provide. The results of this survey have reinforced WID's awareness that the lack of a comprehensive national personal assistance policy consistent with the principles of independent living has contributed to the unnecessary isolation and dependency of untold numbers of North Americans with disabilities.

Given this situation, our foremost recommendation is that a federal personal assistance services policy consistent with the

principles of independent living be established and that a national personal assistance program be developed. This program can be funded by the federal government and private insurers and implemented by the states in accordance with policies and regulations promulgated at the federal level. Just as it took the enactment of Medicare, Medicaid and the Older Americans Act to ensure that older people and poor people receive a more equitable share of this country's medical care and social services, it is now necessary to institute a National Personal Assistance Service Program in order to make personal assistance services available across the United States to all those who could benefit from them.

To this end **WID Recommends: 1) that meetings of federal and state policy makers with representatives of and advocates for people of all ages with all types of disabilities be convened and funded by the federal government. The purpose of these meetings would be to discuss the implications of this study and WID's recommendation in order to develop proposals regarding the development of a national personal assistance program for independent living; and 2) that the federal government study what other countries have done to incorporate personal assistance services into their national social service policy.**

We now present a series of other policy and action recommendations which should guide the development of a National Personal Assistance Services Program. The first thirteen of these were adopted by the National Attendant Care Symposium sponsored by the National Council on the Handicapped. The remaining four policy recommendations have been developed by WID as a result of its research. Following each policy recommendation is a series of recommendations for action in accordance with each suggested policy.

Recommendations

1. The program should serve people with all types of disabilities on the basis of functional need:

WID Recommendations: 1) that every state make personal assistance services available to people with disabilities of all kinds; 2) that more information be gathered on the availability, type of services offered and quality of separate personal assistance service programs for people with intellectual, mental and sensory disabilities; 3) that the extent of need for personal assistance services to these three populations be explored; and 4) that demonstration projects be funded that combine services to these three groups with services to people with physical disabilities and brain injury.

2. The Programs Should Serve People of All Ages:

WID Recommendations: 1) that every state make personal assistance services available to all age groups; 2) that projects be established to look at how children and adolescents who are disabled can benefit from attendant services; and 3) that states consider consolidating programs for different age groups.

3. The program should provide for the optimum degree of self-direction and self-reliance as individually appropriate and offer the users a range of employer/employee and contract agency relationships:

WID Recommendations: 1) that all programs allow users the choice of individual providers or trained home health aides and homemakers from public or private agencies; and 2) that a continuum for managing service delivery be made available, ranging from consumer management (to the maximum extent feasible) to total agency management; and 3) that users of short term periodic services also have the option to locate, screen, train, hire and pay attendants if desired; and 4) that policies be developed that presume consumers prefer self-direction and require an evidential finding that an individual does not want or is incapable of total self-direction.

4. The program should offer assistance with personal, cognitive, communicative, household and other related services:

WID Recommendations: 1) that all rural and urban areas in the U.S. have a program offering the full array of personal assistance services needed by disabled people of all ages and all disabilities - physical, intellectual, mental and sensory; 2) that the states which offer services through separate household assistance and personal maintenance/hygiene services programs establish new programs which combine these services in terms of service delivery as well as organizational structure.

5. The Program should provide services 24 hours a day, 7 days a week, as well as short-term (respite) and emergency assistance as needed:

WID Recommendations: 1) that all programs make services available 24 hours a day, 7 days a week; 2) that a pool of emergency assistants be maintained in every locality; 3) that respite services be established for all age groups in the 16 states that do not offer them and 4) that respite services be available on a long-term (2 - 4 weeks) as well as a short-term regular or periodic basis; and 5) that respite and emergency services be provided in the location the user requests, instead of being restricted to institutional settings.

6. Employment disincentives should be eliminated, and
7. The program should serve people at all income and resource levels on a cost sharing basis as appropriate:

WID Recommendations: 1) that Medicaid benefits or other federal health insurance be made available to disabled workers who are unable to obtain private health insurance at reasonable cost; and 2) that all personal assistance service programs establish an appropriate cost-sharing formula and a realistic income ceiling from which all reasonable disability-related expenditures are excluded.

8. Services should be available wherever they are needed (eg. at home, work, school, on recreational outings, or during travel):

WID Recommendations: 1) that personal assistance be made available to users, not only for personal maintenance, hygiene and mobility tasks and housework, but also for work, school and recreation needs as well; 2) that eligibility requirements not limit the geographic mobility of the individual, so that people needing personal assistance are allowed to travel outside a state and still retain coverage for personal assistance services; and 3) that employers in both the private and public sectors explore the possibility of making personal assistants available in the workplace as is already being done in Sweden (Ratzka, 1986).

9. Personal Assistants should receive reasonable remuneration and basic benefits:

WID Recommendations: 1) that attendants be paid at least 150% of the minimum wage with periodic increases to reflect inflation and growth in experience and qualifications; 2) that attendants receive paid sick leave, vacation and group health insurance benefits in addition to Social Security, worker's compensation and unemployment benefits; 3) that joint discussions between unions and users be instituted to explore ways in which users and assistants can work together to provide better benefits for each other.

10. Training for administrators and staff of administering agencies and provider organizations should be provided.

WID Recommendations: 1) that the legislation establishing the program (as well as the implementing regulations) require that administrators and agency personnel undergo appropriate training; and 2) that qualified disabled persons who use personal assistance services play a significant role in this training nationwide.

11. The program should provide recruitment and training of personal assistants as appropriate.

WID Recommendations: 1) that all personal assistant training programs be imbued with the Independent Living philosophy; 2) that training programs be managed and administered by the Independent Living Centers, wherever possible; 3) that personal assistants be taught that, whenever possible, the bulk of their training will be provided by their clients; 4) that users of personal assistance be instructors in the training program; 5) that training of personal assistants not be mandatory in most cases; 6) that registration and special training be required for those working with people with mental or intellectual disabilities; and 7) that personal assistant referral, recruitment and screening services be available for users who desire them.

12. The program should provide effective outreach and training of consumers as appropriate.

WID Recommendations: 1) that all personal assistance service programs be required to undertake outreach efforts such as visits to rehabilitation centers, sheltered workshops and schools, as well as brochures, public service announcements on T.V. and radio, buses, and so on; and 2) that personal assistance service programs offer both training for consumers in management of personal assistants and follow-up.

13. Consumers should participate to a substantial degree in policy development and program administration.

WID Recommendations: 1) that every personal assistance service program actively recruit personal assistance users to fill administrative and management positions; and 2) that representatives of Independent Living Programs be included on policy boards and state/local commissions which establish personal assistance service policy, rules and regulations.

14. The program should not restrict individual providers from administering medications or injections or from carrying out catheter management.

WID Recommendations: 1) that programs allow personal assistance users to train independent providers in catheter management, injections and medication administration; and 2) that programs ensure that all providers are allowed to provide the full range of services, paramedical as well as non-medical.

15. Family members should be eligible to be employed as individual providers.

WID Recommendation: 1) that all family members be eligible to be paid providers at a user's request; and 2) that a cash "personal assistance allowance" be provided which the disabled

person can use to hire family members or to purchase services from the outside.

16. No one should enter a nursing home or institution unless a finding has been made that they cannot live at home even with personal assistance.

WID Recommendation: that all states institute mandatory programs to screen prospective nursing home admissions.

17. Mechanisms for accountability should be developed that take into account the user's need for independence.

WID Recommendation: that a conference of independent living activists, users and program administrators be convened to discuss the issue of liability more fully.

Conclusion

Personal assistance, particularly attendant services, is crucial to maintaining adults of all ages who are disabled in the community. Recognizing this fact, two key conferences were convened in 1985 by the World Rehabilitation Fund and the National Council on the Handicapped in conjunction with the World Institute on Disability to discuss the state of personal assistance services in the U.S. and Europe. The participants at these conferences - including representatives of the Independent Living Movement, state and national disability organizations, state and federal government, researchers, consumers and advocates - all concluded, along with WID, that a national personal assistance program for independent living must be established.

Maintaining the current non-policy will no longer work. What has emerged on a de facto basis as an outgrowth of existing federal programs is a medical model of personal assistance service delivery which is unnecessarily costly and inadequate. There is an ever growing population of older people needing attendant services and an increasing number of families unable to provide those services.

The situation, in short, is reaching crisis proportions. In order to deal with it, it behooves policy makers to give serious consideration to this study and the recommendations it contains.

THE WORLD INSTITUTE ON DISABILITY (WID) is a private, non-profit 501(c)(3) corporation focusing on major policy issues from the perspective of the disabled community. It was founded in 1983 by persons who have been deeply committed to the Independent Living Movement. Its mission is to promote the health, independence, well-being and productivity of all persons with disabilities. It is funded by foundation grants, technical assistance contracts and individual donations.

WID is a research and information center focusing on five policy and program areas which have significant impact on people with disabilities:

****Attendant Services:*** WID is studying the availability of attendant services around the country and has proposed policy recommendations in this area. It operates a national resource center providing information and technical assistance.

****International Development of Independent Living:*** It has been said that Independent Living is "the hottest new American export today." WID is actively involved in promoting international relations among disabled communities and has hosted visitors from twenty-five countries.

****Public Education:*** WID believes that the general public, disabled people and professionals in the fields of health care, aging, education, housing, job development and transportation need accurate information on disability and independent living. WID is also engaged in consultation and education with synagogues and churches on issues of architectural and attitudinal accessibility for elderly and disabled persons who wish to participate fully in the life of their religious communities.

****Aging and Disability:*** WID has identified the interface between aging and disability as one of its priority areas. It is engaged in ongoing work to build linkages between the disabled and elderly communities. In 1985, WID co-sponsored a major national conference titled, "Toward a Unified Agenda: Disability and Aging."

****Immunization and Injury Prevention:*** The polio virus has once again become a threat to people throughout the world. WID is determined to help eliminate the spread of polio by working with the United Nations and other organizations to make universal immunization a reality. In addition, WID is committed to the prevention of all disabling injuries, diseases and conditions.

Other attendant service publications which can be ordered from the World Institute on Disability, 1720 Oregon Street #4, Berkeley, California 94703:

**Descriptive Analysis of the In-Home Supportive Services Program in California* ($10). Describes one of the most innovative programs in the country. Examines the history of the 25-year-old program, how it operates, who it serves, and its problems.

**Swedish Attendant Care Programs for the Disabled and Elderly: Descriptions, Analysis and Research Issues from a Consumer Perspective* by Adolf Ratzka, Ph.D., published by the World Rehabilitation Fund, 1985 ($3). A consumer-based analysis of the attendant services system in Sweden by an economist who is a user of personal assistants.

*"Report on National Attendant Care Symposium" 1985 ($3). Proceedings from a national meeting sponsored by the National Council of the Handicapped. Includes recommendations for a national policy for attendant services along with recommended changes in existing legislation.

*"Attendant Services, Paramedical Services, and Liability Issues" (Free). Explores the issue of liability of providers of different skill levels performing personal service tasks. Gives consumer-based perspective along with data on how various states deal with the issue.

*"Summary of Federal Funding Sources for Attendant Care" by Hale Zukas (Free). Overview of the provisions for attendant services under Medicare, Medicaid, Social Service Block Grant, The Rehabilitation Act, and Title III of the Older American's Act

*"The Case for a National Attendant Care Program" by Hale Zukas (Free). An analysis of the federal funds presently utilized to finance attendant services, their inadequacy to fulfill the need, and the need for a national entitlement program.

*"Attendant Service Programs that Encourage Employment of Disabled People" (Free). Brief state by state description of programs encouraging employment, giving information on eligibility criteria, administrating agency, funding source, utilization and expenditures.

*"Ratings of Programs by Degree of Consumer Control" (Free). Ratings of each program's degree of consumer control based on the National Council on the Handicapped's ten-point criteria.

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